

## **Recours à l'enquête narrative pour recueillir l'expérience de l'autogestion du diabète dans une population autochtone**

**Sylvia S. Barton**

C'est selon l'approche de l'enquête narrative qu'a été analysée l'expérience de personnes autochtones vivant avec le diabète de type 2 dans une collectivité rurale. La méthode utilisée pour guider la recherche a été l'enquête narrative fondée sur l'herméneutique phénoménologique. Un échantillon de 4 personnes descendant de la nation Nuxalk qui vit à Bella Coola (Canada) a été choisi à dessein. Ces personnes ont été sélectionnées pour leur aptitude à présenter des récits de vie étoffés et à faire apparaître du sens dans leur propre histoire de diabète. Trois principes clés ou interprétations analytiques prédominantes se sont dégagés, qui pourraient contribuer à la recherche sur la santé autochtone d'une manière générale. L'article est axé sur notre compréhension accrue du diabète dans un contexte culturel précis. L'analyse met en relation diverses orientations philosophiques, épistémologiques et méthodologiques avec la recherche auprès de personnes autochtones vivant avec le diabète.

Mots-clés : personnes ou peuples autochtones, descendant de la nation Nuxalk, diabète, enquête narrative

# **Using Narrative Inquiry to Elicit Diabetes Self-Care Experience in an Aboriginal Population**

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A narrative inquiry approach was used to explore the experience of Aboriginal people living with type 2 diabetes mellitus in a rural community. Narrative inquiry based on hermeneutic phenomenological philosophy was the methodology used to guide the research. A purposive sample of 4 persons of Nuxalk ancestry living in Bella Coola, Canada, were selected for their ability to present rich life narratives and to reveal meaning in their particular diabetes stories. Three key insights or overarching analytical interpretations emerged and could contribute broadly to Aboriginal health research. The focus of the article is the expansion of our understanding of diabetes within a specific cultural context. The discussion connects various philosophical, epistemological, and methodological orientations to research with Aboriginal people living with diabetes.

**Keywords:** Aboriginal peoples, First Nations, Nuxalk ancestry, diabetes, narrative inquiry, Aboriginal knowledge, nursing practice, cross-cultural research

A narrative inquiry into Aboriginal stories of diabetes (Barton, 2006) was a research project that came to fruition in response to an epidemic in Aboriginal communities across Canada. The claim of a widespread prevalence of diabetes in Aboriginal communities is found in social epidemiology and cultural and medical anthropology literature focused on the experience of diabetes as it is constructed and lived within the context of Aboriginal culture (Health Canada, 2000; Waldrum, Herring, & Young, 2006; Young, Reading, Elias, & O'Neil, 2000). The purpose of the study was to examine an Aboriginal person's experience of living with diabetes. The methodology guiding the research was narrative inquiry (Clandinin & Connelly, 2000) and dialogue and conversation were used to obtain a "storied" view of experience. The inquiry highlighted my 3 years of co-participation with one man and three women of Aboriginal ancestry, a journey that elicited their rich life narratives and the meaning of their diabetes stories. It entailed 5 years of scholarly and personal exploration, including listening, learning, sharing, and writing in order to gain a cultural view of human experience. These views refer to how I was trying to understand experience as something always shaped by culture. The end result was the co-construction of a diabetes narrative as a process of healing and well-being in an Aboriginal context.

Methodologically, the analysis was guided by three sets of narrative inquiry: theoretical; practical, text-oriented; and interpretive-analytic. Guided by these topics based on hermeneutic phenomenological philosophy, I introduce key insights framed as three overarching analytical interpretations that could contribute broadly to Aboriginal health research. From this position, I draw several conclusions about the importance of conducting research on experiences and narratives of diabetes in a First Nation community. The purpose was to elucidate the personal and human elements, as well as the cultural and healing dimensions, that surfaced through a narrative inquiry approach. The focus of the article is the expansion or transformation of our understanding of diabetes within a specific cultural context. The discussion connects various philosophical, epistemological, and methodological orientations to research with Aboriginal people living with diabetes.

The inquiry was undertaken in a context of little qualitative work on the Aboriginal experience of living with diabetes, and no qualitative work exploring the phenomenon from a cultural perspective based on the existential dimensions of time, place, body, and relationship. This claim is founded on nursing research that argues for a “socialized” understanding of health and illness based on narratives of experience (Garro, 1995; Hernandez, Antone, & Cornelius, 1999; Tarlier, Browne, & Johnson, 2007). The inquiry is meant to contribute to the knowledge base on Aboriginal diabetes health by eliciting the experiences of four extraordinary people in achieving harmony and balancing the states of being Aboriginal, being diabetic, and being well. It does not predict or generalize, but rather attempts to truly understand the diabetic issues and concerns of Aboriginal people, including the significance of diabetes events for Aboriginal people, their families, and their communities. The study is also intended to stimulate inquiry into the diabetes experiences of other Aboriginal peoples whose land is part of Canada, as well as indigenous peoples whose lands are part of countries such as Australia, New Zealand, and the United States.

Theorizing that Aboriginal peoples’ lived experience of diabetes is always constructed within a social, cultural, and political context, I begin with three overarching analytical interpretations that emerged from the inquiry and are based on the participants’ experiences. I then consider the cross-cultural, professional, and theoretical results of these interpretations in terms of health-care research and practice. The inquiry’s contributions to colonial and postcolonial theories concern the complex socio-cultural realities of the Aboriginal experience of diabetes. Research and scholarship informed by postcolonial theoretical perspectives in nursing, for example, show how diabetes narratives are shaped by personal, social, and material conditions and how contemporary understandings of health

and illness are inseparable from perspectives on race, ethnicity, and culture (Anderson, 2000; Anderson et al., 2003; Browne, Smye, & Varcoe, 2005).

In this research, I also asked how non-essentialist views of culture might be developed in nursing, and I grew to appreciate the fact that language use is a critical aspect of the decision not to conflate culture with ethnicity. Certain terms can inadvertently undermine the intent of the research and the rich narrative insights and interpretations. This calls for a description of culture, so that terms such as *cultural differentiation*, *cultural view of experience*, and *cross-cultural* are not interpreted in static and essentialist ways. Thus, as implied in my narrative insights and reflexive stance, culture is best described as a living understanding as expressed narratively, through stories. This is also a view of culture that is based on hermeneutic phenomenological philosophy, which is consistent with the theoretical ground of the research methodology: narrative inquiry.

### **Cultural Differentiations and Diabetes Experiences**

The first overarching interpretation asks how an Aboriginal person living with diabetes experiences the world. It was from such questioning that a desire to know the cultural worlds in which Aboriginal peoples experiencing diabetes live as human beings was satisfied. *Aboriginal experiences of living with diabetes are profoundly different from non-Aboriginal experiences as they have come to be known.* At a time of rapid global change and increasing social, political, and cultural complexity, there is a growing need to view Aboriginal diabetes as an epidemic. Among public, voluntary, and health-sector organizations, there is an urgent need to understand the evolving phenomenon of diabetes as experienced by Aboriginal peoples, to develop strategies based on the stories they are constructing about themselves as diabetic peoples, and to respond to the challenges that shape who they are while living with diabetes as a process of healing and well-being.

The research revealed an awareness of profound cultural differences: an understanding of an Aboriginal diabetic self through George's stories, Aboriginal experiences of diabetes through Emilie's stories, a recognition of diabetes as a gateway to Aboriginal healing through Violet's stories, and Aboriginal reflections of living with diabetes through Hazel's stories. These are rich narratives in which the participants speak of language and spirituality; family and social networks; elders; cultural and communication patterns; diabetes issues and concerns; diabetes care; illness and bereavement practices; and traditional healing options. Their thoughtful, penetrating insights into cultural orientations, into diabetes as a process of healing and well-being, and into underlying belief frameworks reveal

the profound difference between Aboriginal and non-Aboriginal experiences of diabetes.

Consistent with the work of Kelm (1999), the findings suggest that nurses and other health-care providers have a limited understanding of Aboriginal history and the colonial relations that influence Aboriginal health and illness, especially chronic illness. This poor understanding is also likely shaped by “de-socialized” notions of how people experience diabetes as a chronic illness. Postcolonial theories serve to remind us of the forces of colonization that shape health care and people’s experiences of diabetes in ways that are profoundly important to nursing. Like most indigenous groups globally, Aboriginal Canadians have, throughout their history, experienced ethnic destruction, broken treaties, forced displacement, wars, imported illnesses, legal discrimination, and human rights abuses. Although their health circumstances are improving, they have the shortest lifespan of any ethnic group in the country and continue to experience some of the highest mortality and morbidity rates. The cultural orientations inherent in the notion of an Aboriginal diabetic self are entwined with notions of Aboriginal identity. One cannot generalize when speaking of Aboriginal Canadians, because the cultural orientations of an Aboriginal people are unique to their particular tribal community (e.g., the Nuxalk Nation of Bella Coola) and to their influence on the formation of a diabetic identity. Essential to the harmonious balancing of diabetes, culture, and wellness is recognition of the fact that Aboriginal people with diabetes have many stories to tell and that these stories need to be valued and to be accorded the same respect as life stories.

In non-Aboriginal cultures, learning is sometimes separated from experience. Although some Western epistemologies and philosophies of science (i.e., Cartesian) may disconnect knowledge and experience to some degree, there are many epistemologies that do not. For the scientist Michael Polanyi (1969), for instance, experience is the basis for all inquiry and knowledge. Also, there are many non-Aboriginal postmodernist scholars who do not separate learning from experience; these include scholars working from a critical feminist location (hooks, 1989) and those exploring relational epistemologies (Thayer-Bacon, 2003) or social constructionist learning theories. In traditional Aboriginal teachings, experiences are always connected to learning. Inquiry into the Aboriginal experience of diabetes concerns the holistic experience of living with the disease. It begins with an Aboriginal person who is living with diabetes and experiencing healing and wellness, not just weakness and sickness. George, Emilie, Violet, and Hazel tell us what it is to be a diabetic person experiencing wellness. They know that, if they start there, the strength and resources within other Aboriginal people who have diabetes will be seen first. They are aware of the need to shift away from the

labelling of people with diabetes and from a focus on diabetes as pathology. Yet the more one attempts to explain diabetes, the more one removes it from its context.

In sharing their Aboriginal stories of diabetes, the participants did not try to define an experience of diabetes; rather, they always located it within a context of living and values. Diabetes is, then, seen as a living thing, just as Aboriginal cultures must be viewed as living things. When Aboriginal experiences of diabetes are explored as living things, they become complex things, because they will vary. The Aboriginal stories of diabetes told by the participants may not change, but those who hear them will change. Those who hear the diabetes stories again and again over time, and acquire different experiences, will come to truly understand them and be influenced by them.

In terms of context, language and spirituality are critical factors. The primary language of the participants was English, and cultural differentiation was revealed through various Aboriginal phrases and words that often were worked into everyday speech. Some of the participants still knew their Native language but spoke of experiencing interruptions in speaking the language of their ancestors, then relearning the language and passing it on through special cultural classes held in the school located in their community. From a spiritual perspective, the participants mixed some form of Christianity or other religion with Native spirituality, which they spoke of practising in ways that guided their approach to life, including their diabetic life, in a sacred and holistic manner.

In terms of family and social structure, the participants placed great emphasis on children, family, and extended family, revealing how the notion of family formed the basis of their Aboriginal societies. Depending on the particular social experience or situation, the participants also spoke of their cultures as placing a heavy emphasis on individuality, equality, and the important roles played by each person in the family, the group, the community, and the society. Each participant placed great value on the elders and their practical knowledge, including diabetes experiential knowledge. The participants spoke of teaching younger people to always treat elders with respect and to be responsible for bringing honour upon one's family, tribe, ancestors, and community.

The participants revered their elders and ancestors for their wisdom, knowledge, and advice. They spoke of the tensions that now existed in some families as a result of acculturation, poverty, and the breakdown of traditional Native society, but also of the continuing acts of reverence towards the elderly. By telling their Aboriginal stories of diabetes, the participants sought to view the world from different eyes and to move away from one pattern of diabetes practices to embrace many ways of responding to diabetes. They played an important part in decisions that affected

the well-being of the family, particularly in terms of the love extended to children and grandchildren. They also played a significant role in decisions that affected the healing and well-being of family and community members with diabetes as well as in the healing process and wellness.

Part of the Aboriginal healing process and wellness with regard to diabetes is realizing that there are many ways of perceiving the world. The participants did not tell just one story. They told many stories, in order to share as many perspectives as possible, because that is what is entailed in finding harmony. Harmony exists only as a result of difference, because everyone will not experience diabetes in the same way. This diversity is inherent in finding a harmonious balance between diabetes, culture, and wellness. Recognizing diabetes as a gateway to Aboriginal healing, the participants viewed diversity as something to be celebrated. Their cultural style of communicating was reserved, thoughtful, and subtle, their feelings and emotions expressed in a direct way. Their voices were always calm, soft, and polite, their conversation characterized by long pauses, silent reflection, metaphor, and more stories.

From a healing and wellness perspective, the participants' narratives reflected both difficulty and ease with accessing diabetes care in their community. Transportation and geographic barriers posed by living in Bella Coola were significant, particularly if the weather was harsh or if there were health-care providers who were new. This was part of the healing perspective and a way of recapturing one's wholeness. Part of finding that wholeness were stories about the valuing of traditional healing practices mixed with stories revealing both comfort and discomfort in seeking care from health professionals in a clinic or hospital. Within those contexts, the participants spoke of family and community members experiencing many conditions besides diabetes, including obesity, alcohol misuse, and accidents that were fatal or resulted in severe, disabling injuries.

Diabetes as a gateway to Aboriginal healing and well-being is about the reclamation of wholeness. It is about forming diabetic identities, retaining one's language, reclaiming spirituality, and whatever it is that makes a difference. It is about a healing and wellness process in the sense of reclaiming wholeness of mind, body, and soul. And it is about reclaiming wholeness of the universe, perceiving balance and imbalance within it, because human beings are reflections of the wellness of the universe. The healing process is not only making food choices within perceptions of a modern diet consisting largely of starch, refined carbohydrates, and fat, but also those steps taken to heal Mother Earth. Our consumption of her, just as with fresh fruit, vegetables, and traditional foods, has changed over time, due to a variety of factors. On a grandiose scale it relates to our need for a higher standard of living, and on a small, practical scale it

relates to Aboriginal people's limited incomes, availability of consumer goods, and acculturation. Another influential factor, however, was the change in the participants' diets related to living with diabetes and eating the particular foods that make a diabetic person heal and feel well. These changing conditions were expressed along with physical symptoms such as aches, pains, and fatigue. They were also combined with emotional dependency, which was perceived as caused by one's disharmony with the environment, with the spiritual world, and within personal relationships. The participants' stories revealed that mental imbalances can be seen as resulting from violations of cultural prohibitions, negative energy, and evil spirits. They also revealed that spiritual practices and traditional ceremonies are part of the pursuit of harmony between being diabetic, being Aboriginal, and being well.

The participants recognized a variety of treatments for diabetes, a condition they viewed as having been introduced to indigenous cultures by outsiders; they considered mainstream medical care to be the most appropriate treatment. Their stories revealed that diabetes is at times treated concomitantly with traditional medicinal, spiritual, and ceremonial purification practices. Their stories also related Aboriginal experiences of alcohol misuse, which was considered an extreme reaction to one's imbalance in relation to self, others, and the world. These stories about alcohol misuse were connected to those about loss of culture, identity, and Aboriginal souls.

Last, Aboriginal reflections of living with diabetes had to do with interpreting a sacred phenomenon: the participants always spoke of reclaiming wholeness as sacred work. The interconnected narratives comprised stories of bereavement and of family members and friends visiting an ill or deceased person. Depending on how traditional the people in the stories were, those visited would be the subject of a variety of healing ceremonies, often performed communally. The stories told of the spirits of the dead being honoured regularly for generations, and of death being merely the beginning of a journey into the next world. These stories in particular demonstrated the profundity of the participants' belief in the healing power of plants and herbs, their strong connection to the earth and the universe, and their deep respect for all things, both living and non-living.

These reflections on more sacred work led to stories about healing and wellness frameworks that were holistic, combining physical, mental, emotional, and spiritual well-being. Physical problems were understood as usually caused by emotional, mental, spiritual, and physical imbalances. Harmony and a sense of balance in all things, including mind, body, spirit, and the environment, were considered important to a sense of wellness. The participants helped me to interpret their healing beliefs

related to diabetes as more circular and indirect than the linear cause-and-effect view of mainstream medicine. Thus diabetes as a process of healing and well-being cannot be separated from spirituality; it goes beyond religion to reflect the interconnectedness, sacredness, and balance of all things.

### **Existential Understandings of Aboriginal Diabetes**

The second overarching interpretation stems from the discovery of an existential framework by which the participants' life narratives and Aboriginal stories of diabetes were understood. *Existential understandings of diabetes in relation to time, place, body, and relationship are connected to an Aboriginal person's distant past, recent past, and present life.* It appears that, due to a demand for evidence-informed practice, analysis, and understanding, organizations that would never have done so in the past — or would not have done so with such intensity — are now conducting social sciences and humanities research focused on experience. The knowledge generated by having Aboriginal people tell their stories of diabetes is providing alternative interpretations of the tensions and conflicts that emerge in a world rife with consequences, values, politics, and moral dilemmas.

Based on an existential framework for interpreting the meanings in Aboriginal stories of diabetes, time was revealed to be a dimension in which past, present, and future are a continuous whole and in which the diabetic self is embedded within one's life narrative. The sense of place described in the stories not only revealed a dimension in which situation renders inseparable Aboriginal people, the land, and their stories, but also elucidated how Aboriginal experiences of diabetes are embedded within one's life narrative. The body was revealed to be a dimension in which the physical presence is both visible and concealed to oneself and others and also a dimension that elucidates the ways in which diabetes as a gateway to healing is embedded in one's life narrative. And the interpretation of relationship revealed a dimension in which human beings are interconnected with others and also elucidates how Aboriginal reflections of living with diabetes are embedded in one's life narrative.

One is much more likely to appreciate the details of such interconnectedness of cultural knowledge, which has implications for diabetes practices, diabetes research, and health policy, if they are presented through the existential notions of time, place, body, and relationship. Existential understandings of diabetes are firmly connected to an Aboriginal person's distant past, recent past, and present life in terms of the notion of an Aboriginal self, inquiring into Aboriginal experiences of diabetes, recognizing diabetes as a gateway to Aboriginal healing, and interpreting Aboriginal reflections of living with diabetes. Such a frame-

work also allows for a sense that culture is only one of many factors that influence healing and well-being. Age, gender, income, literacy, education, lifestyle, amount of time in a particular location, personality, and so on are equally important to a holistic understanding of Aboriginal experiences of diabetes.

Such contemplation from multiple viewpoints will contribute to the creation of a platform of human understanding upon which social structure and human agency intersect. Further, acts of conducting research, questioning, and theorizing serve to enrich our quest to know ourselves, our histories, our cultures, and our successes and failures, all of which shape our being in the world with others. During the present inquiry, I experienced a pedagogy of thinking and doing (theory and practice) by serving as witness to the Aboriginal stories of diabetes. By pedagogy, I mean the process of teaching, treating, responding, educating, or generally being with Aboriginal people who have diabetes, which requires constant acting in situations of experience and relationship.

Last, an existential understanding of Aboriginal diabetes underlines the importance of valuing an alternative culture of research through a focus on relationship. The concept of relationality is key to increasing engagement with the knowledge hidden within Aboriginal experiences of living with diabetes. It was viewed from a critical cultural perspective that infers relationality in context, with an understanding that it is shaped by social, political, and historical factors (Doane & Varcoe, 2005). In terms of what relationality looks like in the context of the researcher-participant relationship, the choice of a relational methodology — narrative inquiry — located Aboriginal epistemology within it. Methods provided ways to develop awareness of identities and power differentials that existed in the process of conducting research. An equitable relationship between the researcher and the participants, for instance, was achieved through the narrative inquiry process of co-participation and co-construction of Aboriginal stories of diabetes, resulting in feelings of empowerment by participants.

Thus, relationality led to other questions about meaning that arose from further interpretation, originating from a storied landscape of Aboriginal diabetic knowing. This is a particular kind of knowing that recalls Smith's (1994) writings on the hermeneutic imagination and the pedagogic text. How can we orient our lives with those of Aboriginal people who are experiencing diabetes when we can no longer take for granted what the Aboriginal diabetic person is, in any discrete sense? How can we orient our lives with theirs when we do not make problematic all of the usual categories for understanding Aboriginal experiences of diabetes in our mainstream culture (high blood glucose levels, behavioural non-compliance, obesity, etc.)? And how can we orient our

lives with theirs when we consider questions of meaning of Aboriginal diabetic identities as those which cannot be answered except self-reflexively — that is, from the question of who I am in relation to my practice and research? These are questions that require serious consideration if they are to be answered in ways that entail authentic relational action.

### **Acts of Mutual Respect and Caring**

The third overarching interpretation originates from doing research on the diabetic person's secrets and intimacies, which constitute the world of diabetes and require that acts of caring be part of the research process (van Manen, 1998). *Mutual respect, as in Aboriginal experiences of being honoured, may be understood as the ways in which one person thinks and behaves towards another person through acts that express high regard and caring.* One is reminded of the words of Goethe (1963), "One learns to know only what one loves, and the deeper and fuller the knowledge is to be, the more powerful and vivid must be the love, indeed the passion" (p. 83). In other words, loving the people one knows allows one to know the people one loves. This makes me connect my own personal experience of becoming a mother to my deepened and fuller knowledge of relationality within the family. From a new angle, I am discovering, by being in relationship with my daughter, what love is, why it has to be shared, and how my passion for my daughter feeds me so genuinely. It is interesting that people tend to relate more lovingly to each other when children are present. We all have an enormous capacity for loving, and my daughter reminds me every day that we must give energy to others. I am gaining from my daughter a deeper sense of what people experience when they want to have more relationships in their lives, want to love within all of these relationships, and want to be loved within them in infinitely different ways. Family has become for me an island of light, amusement, and wisdom. It is a place I run to with my discoveries, torments, and hopes, at any time of day, and feel welcomed.

In the retelling of our professional relational experiences, caring acts, love, and passion need to be recognized and acknowledged in our work together. The sharing of such personal reflections and what they mean may contribute to the creation of new scholarship possibilities. In our research, we need to aspire to the kind of scholarship that fosters partnerships characterized by culturally competent practice and that promises to benefit Aboriginal people themselves. This depends on relationality, but our health-care and research systems hold new possibilities for dialogue — possibilities for people to develop the ability to interpret their inner and outer worlds and to find the strength they need to overcome their specific diabetic challenges. It is through that inherent strength that

they come to realize that their responses to diabetes are often experienced concomitantly with the trials and tribulations of a host of other illnesses, adversities, and tragedies.

These kinds of research partnerships, which do not shy away from relationality with Aboriginal participants, if on the right track, will raise questions about the ownership of knowledge, as well as the ethical questions and dilemmas that emerge from experiences of being in relationship with Aboriginal peoples. It will also require researchers to ask themselves what it means to be in respectful relationships with Aboriginal participants. Wilson (2003) explains:

The concept of relationality permeates recent scholarly writing by Indigenous scholars. They question whether in fact it is even possible for [colonial] system researchers to understand this concept with the depth that is required for respectful research with Indigenous peoples. (p. 173)

The issue of relationality is key to Aboriginal diabetes research. It determines what kind of relationship Aboriginal people want with researchers, both non-Aboriginal and Aboriginal, and the ability of Aboriginal people to work with practitioners. We need to ask whether it is even possible for practitioners and educators to understand this concept with the depth that is required in order to provide respectful diabetes care for Aboriginal people. It is in contemplating such questions, I believe, that this inquiry informs and offers guidance with respect to culturally congruent care, or “sensitive, creative, and meaningful care practices to fit with the general values, beliefs, and lifeways of clients” (Leininger & McFarland, 2002, p. 12). The inquiry also offers guidance with regard to cultural safety, which is awareness of power imbalances, the nature of interpersonal relationships, and institutional discrimination, whereby the recipients of care decide whether or not they feel safe with the care given, the level of trust established, and differences in perceptions identified and negotiated (Browne & Fiske, 2001).

As a person with nursing practice, education, and research experience, I believe that health professionals who conduct research are in an excellent position to contribute relational, culturally competent expertise in diabetes-related practice, education, and research. Cultural competence may be defined as “the explicit use of culturally based care and health knowledge in sensitive, creative, and meaningful ways to fit the general lifeways and needs of individuals or groups for beneficial and meaningful health and well-being or to help them face illness, disabilities, or death” (Leininger & McFarland, 2002, p. 84). It will be meaningful, however, only if it incorporates Aboriginal perspectives and theoretical explorations of culture, as well as cultural differences and context-specific knowledge about poverty, into the relationality and dialogue of cultur-

ally competent work, and only if it considers the time required to establish, maintain, and sustain relationships within active, busy lives.

But as a result of enlightened leadership within research, pressing Aboriginal health issues are being addressed, new approaches adopted, and new methodologies applied. At the same time, scholars who conceive of knowledge development as a social and communicative process are in a position to close the gap that exists between theory and story. Much of what we do as social and cultural beings is to tell our stories. It is only through the personal expertise needed to negotiate a relationship based on authentic mutual respect, which is also reciprocal, shared, and constantly interchanging, that knowledge derived from understanding Aboriginal experiences emerges.

Last, the narrative inquiry was about eliciting from life stories the insight, essence, and resonance of our philosophical and cultural expressions and our desire for them to be recognized. Congruent with Aboriginal ontology and epistemology, the relationships formed were about witnessing a contemplative effort by Aboriginal people to reclaim confidence in their identities, impart a political voice, and heal from colonial injustices. It was about developing a relationship with four participants in order to know a whole life. As a result, the participants were *at home* with the study, as was I as the researcher.

Thus the concept of relationality as part of an alternative research culture recognized the unity or coherence of a life story in which the experience of living with diabetes as a process of healing and well-being was nested. It was about new ways for the participants and the researcher to engage with each other. It was also about analyzing the existence of temporality, memory, and imagination, which influenced both the participants and the researcher as well as our experiences of the research process itself. I believe that relational forms of inquiry will advance nursing development and practice beyond the boundaries established by methodologies that claim to know another culture on the basis of brief encounters. Thus continuous reflection on the concept of relationality within the inquiry provided me with ways of conducting research with George, Emilie, Violet, and Hazel, all of which spoke “narratively, to the ebb and flow of our overlapping lives, and to the creative new ways research by nurses can be developed and practiced” (Barton, 2004, p. 525).

### **Cross-Cultural Contributions**

In examining the cross-cultural contributions, I focus on what the inquiry can mean to Aboriginal people living with diabetes, to their families, to their communities, and to the world. Included are reflections on

Aboriginal diabetic issues and concerns within a context of cultural differentiation, cultural complexity, and cultural interaction. The cross-cultural evidence includes notions of being diabetic, being Aboriginal, and being well, within an Aboriginal framework of diabetic seasons. Themes within the diabetic stories could help to lay the foundation for sounder social health policies. The intention is to reveal yet other ways that the Aboriginal diabetes experience may be positioned amid streams of thought. As van Manen (1998) suggests, “to *know* the world is profoundly to *be* in the world in a certain way, the act of researching — questioning — theorizing is the intentional act of attaching ourselves to the world, to become more fully part of it, or better, to *become* the world” (p. 5).

Diabetes, crises, stress, illness, and aging exist in all societies. Each culture has developed its own ways of defining well-being and making sense of physical, mental, emotional, and spiritual imbalances, its own ways of preventing or responding to disharmony within healing paths, of managing physically altering events and phases, and of establishing roles and behaviours for both health professionals and recipients of diabetes care. The behaviours encompassing diabetic disharmony and well-being are not ones we possess at the point of diagnosis but rather ones that we learn and share through cultural processes over time.

Aboriginal perceptions of place consider hidden connections between humanness and the natural world. Aboriginal perceptions of body consider the deep significance of healing and well-being while living with diabetes. And Aboriginal perceptions of relationship consider honouring the diabetic self whose identity evolves beside family, friends, and community.

It was not until I spent time in First Nations communities as an outpost nurse, living partly with Aboriginal people, that I began to observe lives in self-transformation, self-reflection, and self-learning. It was there that I developed an appreciation for diabetic issues and concerns within a context of cultural complexity. This appreciation led to a true recognition of the cultural differences between colonial views of health and illness and Aboriginal views of healing and well-being — to a witnessing of culture(s) as context and interaction.

There, amidst the nursing realities of sparse living conditions and historical and religious influences, I began to take a deep interest in the quality of life. This enabled me to position myself as a researcher alongside participants in a relational landscape. Thus this inquiry into the Aboriginal experience of diabetes had its beginnings in my advanced nursing practice, where I developed a fascination with the circumstantial nature of our lives. I began to listen as I had never listened before — actively, sensitively, emotionally, and viscerally.

### **Professional Contributions**

The narrative inquiry provides health professionals with reflections on practical matters arising from a concern with ethical issues and cultural pluralism, development of culturally competent knowledge, programs of diabetes care, and social health-care policy. The fundamental emphasis of the health professions on understanding and treating diabetes (medicine) or understanding and treating human responses to diabetes (nursing) lends itself to a concern for Aboriginal cultures. Indeed, it is primarily through nursing that I have discovered a deep interest in culture as an experiential phenomenon. It is the complex concept of Aboriginal cultures that lies at the heart of the difference between understanding and treating diabetes, or understanding and treating human responses to diabetes, both effectively and ineffectively.

When as health professionals we correct abnormal blood glucose levels, adjust oral glycemic medication, or prescribe antibiotics for infection, we seldom consider the cultural influences on an Aboriginal diabetic person. I would like to believe we are beyond the view that diabetes is diabetes whether it is managed in the city of Vancouver, in the Bella Coola Valley, or in rural British Columbia. But the reality is that because of our colonial tendency to view diabetes through a lens of human physiology, we focus much less on understanding it through a lens of relationality in the context of traditional and contemporary medicine.

The primary focus of health professionals is not just the provision of treatment per se, but the Aboriginal person who decides to receive the treatment, heed the advice, and persist with the changes inherent in a challenging diabetic life. Nursing and the health professions, therefore, are profoundly influenced by ethical issues and cultural pluralism. Even in situations where traditional medicine has been severely colonized, there exists a context of traditional medicine where being diabetic, being Aboriginal, and being well are located. It is in those situations that Aboriginal interest in the effectiveness of traditional remedies for the management of symptoms related to being ill reveals aspects of cultural pluralism. And it is in those interpretations where Aboriginal interest in the effectiveness of traditional remedies for the management of symptoms related to being ill reveals aspects of cultural pluralism.

It is in the integration of ideas about Aboriginal healing drawn from family and community medicine, and reflective of physical, mental, emotional, and spiritual well-being, with colonial medicine that responses originate and are sometimes made visible. Aboriginal people learn to honour these connections between thinking and wisdom, and then act on those perceptions of body, mind, and emotion, deriving from the

spirit the humanness that guides their understanding of diabetes. It was by being with Aboriginal people in all facets of storied life that I could witness the turning of the pages of diabetes stories. They were stories within stories, and they spoke of ethical issues and cultural pluralism as a result of living with diabetes, whereby a humbling, compassionate, and honoured existence became known. Thus only slowly and gradually, and only because of patience and a desire to inquire narratively, did I succeed in learning something of significance.

When Aboriginal people are given a reason to share their life stories, a glimpse into their identity stories reveals an ethic guiding their humanness. This ethic directs the colourful threads of a life — the depth of existence to live by, to be transformed by, and, through transcendence, to be remembered by. It is where the underlying principles of balance, harmony, and respect, which are common across the indigenous world, provide the foundation for the development of culturally competent knowledge and diabetes programs of care. Aboriginal life stories invite one to listen, and listen again, to Aboriginal diabetic self-stories. They leave us with a deep sense of what it means for an Aboriginal person to live a life through the influences of traditional and contemporary medicine, where issues of self-government, socio-economic development, and environmental protection are not separated from community health development. This is where Aboriginal social health policy is best realized — not in the inertia of broad social structural change but in the changes that occur through community-based diabetic initiatives. Thus the concept of diabetic healing, which integrates traditional medicines and professional services, may be considered a significant, culturally safe development.

Health professionals need to connect with Aboriginal people who have diabetes, recognizing that each person is part of a family and a historical community — a place within the *stream of time*. We need to connect with families and communities in order to affirm and value the language, cultural practices, and knowledge of the people, in partnership with them, in order to build new relational practices that overcome the colonial remnants — *images of time*. We need to pay attention to the realities of the communities where we practise and live. We have a responsibility to participate in the creation of new possibilities for dialogue, as in an existential understanding of diabetes as the *sugar clock*. And because effective practices of health professionals take place in relationship with Aboriginal people, who experience diabetes within an unfamiliar body, we need to keep in mind their broader existence and the complex historical contexts of culture, ancestry, and environment. We begin to negotiate a relationship with an Aboriginal person in the midst of *feeding the diabetic body*, dealing with *exercise and body weight*, and trying to manage

*body discomfort*. We explore, in respectful ways, how to walk with them through intersections of multiple world views and perspectives in relation to *working on the diabetes* and *figuring the diabetes out*.

### Theoretical Contributions

An inquiry into Aboriginal stories of diabetes must be situated within the complexity of sociocultural realities. What sociocultural realities are socially significant for our understanding Aboriginal experiences of diabetes? Critical social theorists (Freire, 1990; Habermas, 1971) and post-colonial theorists (Bhabha, 1994; Thomas, 1994) would argue that any in-depth analysis must include, in addition to cultural difference, the influence of the colonization and power relationships within which diabetes, healing, and well-being take place. In the present inquiry, the stories of four people living with diabetes were intended to illustrate how, in their daily lives, these people attended to both culture and colonization. They all, in different ways, integrated language and cultural knowledge into their lives and drew upon cultural norms and values. In doing so, they developed equitable relationships and processed the influences of colonization.

Within the stream of thought of critical social theory lies the potential for developing a critical consciousness within a shared view of the dialogical and developmental human being. The inquiry captured the social significance of the concept of self and the capacity for transformation. By focusing on four Aboriginal elders living with diabetes, the inquiry elicited a view of the transformative self within their positive, non-stereotyped construction of images, which revealed Aboriginal reflections of *honouring the diabetic self*. These were people who passed on traditional knowledge, especially traditional healing knowledge, and who, through special connections to the healing spirit, had strong cultural as well as diabetic identities. They illuminated a notion of human enlightenment that was *walking in both worlds*, which was revealed to themselves and others as the ability to engage in culturally overlapping realities.

In terms of colonial power relationships within Aboriginal stories of diabetes, the experiences and situations of the participants contained remnants of their relationships with health professionals, particularly during initial relational encounters. As a result, I was able to discern how the four people sought places and ways in which to develop relationships outside the formal relationships of health and illness with their inherent or assumed hierarchical structure. Hospitals and clinics can be intimidating places for any diabetic, more so for a diabetic whose healing experiences have not always been favourable and have at times been painful. The participants had vivid memories of colonial relationships, consisting

of authority, control, and unilateral decision-making, which in fact still existed outside the traditional medicine system followed in their Aboriginal community.

The type of relationship sought by these elders was in fact more of a partnership, in which *a diabetic self is revealed to others* — people who can be trusted. The traditional colonial relations between non-Aboriginals and the community were being replaced by meaningful community participation in a school curriculum framed by language and culture and by the active pursuit of family involvement and support. Such strategies had resulted in *a diabetic sense of community* — a view of diabetes care and awareness located within teaching-learning-sharing relationships between diabetics, health professionals, and community members and based on a relational philosophy, whereby each person with diabetes is part of a family and a community. By using cultural norms in their life stories, the participants illustrated their respect for Aboriginal beliefs and practices related to traditional medicine. They brought to life notions of Aboriginal holism, the use of metaphor in thought and speech, and existential understandings of diabetes that included time as *cultural time* and place as the *resonance of lived space*.

In terms of the relational literature, I discovered amid indigenous scholarly writings, such as those of Battise (2000) and Smith (1999), a focus on social struggles enacted in social practices wherein Aboriginal people encounter an ethnocentric perspective, authoritative relationships, racist attitudes, and prejudicial perceptions of inferiority or deficits. I came to realize that conditions such as these have been experienced in colonial systems of health care, causing some Aboriginal people to resist the oppression by participating as little as possible.

George, Emilie, Violet, and Hazel, despite the obstacles, have engaged and even excelled in acts of diabetic healing and well-being, in part because, as told in their stories, they have attended to issues of both culture and colonization. Their stories have, in a holistic way, incorporated Aboriginal culture, language, community norms, and values, their mutually respectful relationships helping them to process the influences of tragedy and hardship. It was not only what they did, but how they did it, that was significant. Their stories tell of interrelationships and connections not only to people but to the past (*echo of the past*) and to present-day *situations and experiences*.

Their narratives are not yet complete. They are part of an ongoing discovery of how living with diabetes can serve to overcome ineffective diabetic practices and can involve other diabetics, families, and communities in knowing a world of diabetes that is not only forgiving but accommodating and gracious. They bring to life diabetic notions that contain lessons for others living with diabetes and also demonstrate respect for

different contextual relationships. The stories advance practice and research in relation to Aboriginal experiences of diabetes, for what happens in their narratives cannot be separated from their daily lives with other diabetic people or with families, friends, or the community in which they live. Thus George, Emilie, Violet, and Hazel *become the space they are in*, whereby the focus of diabetes as a practice of healing and well-being is the creation of opportunities for listening, learning, and sharing in *landscapes of transformation*.

### Conclusion

Three overarching analytical interpretations emerging from the inquiry can contribute broadly to Aboriginal health research. I have been able to draw several conclusions about the importance of conducting research on the experiences and narratives of diabetes in a First Nation community. The purpose of the inquiry was to expand or transform our understandings of diabetes within a specific cultural context. The discussion centred on various philosophical, epistemological, and methodological orientations to research with Aboriginal people living with diabetes.

The elicitation of Aboriginal life stories and diabetes stories within a process of narrative inquiry provided an opportunity to look for material supporting alternative explanations within cultural experiences of diabetes. Each interpretation was plausible because of its supporting contextual evidence. The inquiry served to highlight the value of analyzing stories at a universal as well as local level over a number of years.

The inquiry was also intended to help nurses and interdisciplinary health-care providers better understand diabetes in Aboriginal communities. The rich descriptive insights of the Nuxalk culture and its connection to the narratives of diabetes provide a context for understanding how diabetes can and ought to evolve in nursing research and practice. The interpretations presented are rich and local. It was through this awareness and methodological approach that I theorized the complexity of the diabetes experience within a First Nation community and how such knowledge can help nurses to engage with and promote the health of First Nations peoples.

The process of translating aspects of Aboriginal healing philosophy into practice also entailed my interpretations as a co-participant with the four Aboriginal people living with diabetes. A synthesis and discussion of those interpretations through the cross-cultural, professional, theoretical reflections responded to questions about the landscape of the Aboriginal diabetes experience in Canadian society (Clandinin & Connelly, 2000). Such reflexivity revealed the participants' narratives of diabetes as well as the creative responses and adjustments that existed in their diabetes and

life experiences. It displayed the insights circumscribed by relationships, history, and the land, as well as favourable constructions of Aboriginal healing needs and identities, which can lead to improved Aboriginal health generally. It puts forward a more balanced perspective of the Aboriginal experience of living with diabetes in a thriving knowledge society. It is a location where opportunities to peer into the narrative spaces of understanding and explanation that emerge from identity stories make a difference in a world of growing cultural integration, increasing social complexity, and rapid technological change.

## References

- Anderson, J. (2000). Gender, "race," poverty, health, and discourses of health reform in the context of globalization: A post-colonial feminist perspective in policy research. *Nursing Inquiry*, 7(4), 220–229.
- Anderson, J., Perry, J., Blue, C., Browne, A., Henderson, A., Khan, K. B., et al. (2003). "Rewriting" cultural safety within the postcolonial and postnational feminist project: Toward new epistemologies of healing. *Advances in Nursing Science*, 26, 196–214.
- Barton, S. (2004). Narrative inquiry: Locating Aboriginal epistemology in a relational methodology. *Journal of Advanced Nursing*, 45, 519–526.
- Barton, S. (2006). *Spirit winds: A narrative inquiry into the Aboriginal stories of diabetes*. Unpublished dissertation, University of Alberta.
- Battiste, M. (2000). *Reclaiming indigenous voice and vision*. Vancouver: UBC Press.
- Bhabha, H. (1994). *The location of culture*. New York: Routledge.
- Browne, A., & Fiske, J. (2001). First Nations women's encounters with mainstream health care services. *Western Journal of Nursing Research*, 23(2), 126–147.
- Browne, A., Smye, V., & Varcoe, C. (2005). The relevance of postcolonial theoretical perspectives to research in Aboriginal health. *CJNR*, 37(4), 16–37.
- Clandinin, J., & Connelly, M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco: Jossey-Bass.
- Doane, G. H., & Varcoe, C. (2005). *Family nursing as relational inquiry: Developing health-promoting practice*. Philadelphia: Lippincott Williams & Wilkins.
- Friere, P. (1990). *Pedagogy of the oppressed*. New York: Continuum.
- Garro, L. C. (1995). Individual or societal responsibility? Explanations of diabetes in an Anishinaabe (Ojibway) community. *Culture, Medicine and Psychiatry*, 40, 37–46.
- Goethe, W. (1963). *Goethe's world view, presented in his reflections and maxims*. New York: Frederick Ungar.
- Habermas, J. (1971). *Knowledge and human interests* (J. J. Shapiro, Trans.). Originally published 1968. Boston: Beacon.
- Health Canada. (2000). *Diabetes among Aboriginal people in Canada: The evidence*. Ottawa: Author.

- Hernandez, C. A., Antone, I., & Cornelius, I. (1999). A grounded theory study of the experience of type 2 diabetes mellitus in First Nations adults in Canada. *Journal of Transcultural Nursing, 10*, 220–228.
- hooks, b. (1989). *Talking back: Thinking feminist, thinking black*. Boston: South End.
- Kelm, M. (1999). *Colonizing bodies: Aboriginal health and healing in British Columbia, 1900–50*. Seattle: University of Washington Press.
- Leininger, M., & McFarland, M. R. (2002). *Transcultural nursing: Concepts, theories, research and practice*, 3rd ed. New York: McGraw-Hill.
- Polanyi, M. (1969). *Knowing and being*. Chicago: University of Chicago Press.
- Smith, D. G. (1994). *Pedagogy: Meditations on pedagogy and culture*. Bragg Creek, AB: Makyo Press.
- Smith, L. (1999). *Decolonizing methodologies: Research and indigenous peoples*. Dunedin, NZ: University of Otago Press.
- Tarlier, D. S., Browne, A. J., & Johnson, J. (2007). The influence of geographical and social distance on nursing practice and continuity of care in a remote First Nations community. *CJNR, 39*(3), 126–148.
- Thayer-Bacon, B. J. (2003). *Relational "(e)pistemologies"*. New York: Peter Lang.
- Thomas, N. (1994). *Colonialism's culture: Anthropology, travel and government*. Princeton, NJ: Princeton University Press.
- van Manen, M. (1998). *Researching lived experience: Human science for an action sensitive pedagogy*. London, ON: Althouse Press.
- Waldrum, J. B., Herring, D. A., & Young, T. K. (2006). *Aboriginal health in Canada: Historical, cultural, and epidemiological perspectives*. Toronto: University of Toronto Press.
- Wilson, S. (2003). Progressing toward an indigenous research paradigm in Canada and Australia. *Canadian Journal of Native Education, 27*(2), 161–178.
- Young, T. K., Reading, J., Elias, B., & O'Neil, J. (2000). Type 2 diabetes mellitus in Canada's First Nations: Status of an epidemic in progress. *Canadian Medical Association Journal, 163*, 561–566.

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